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PRACTICAL STEPS TO STRENGTHENING HIV/AIDS SURVEILLANCE IN THE EUROPE AND EURASIA REGION: A FIELD GUIDE

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ABOUT THIS FIELD GUIDE

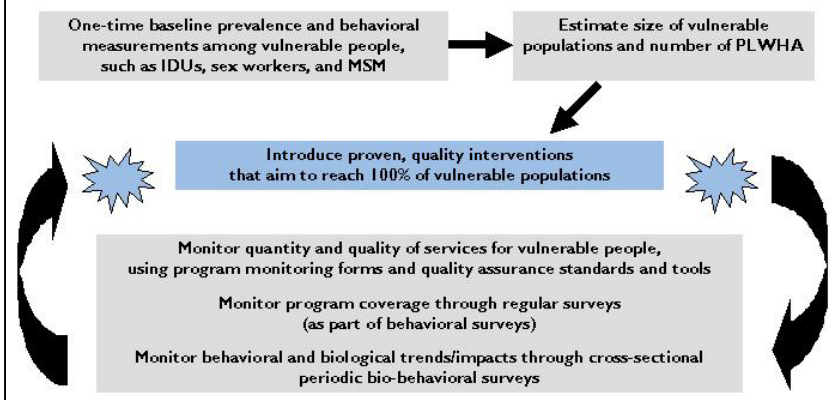
This field guide was commissioned by the Europe and Eurasia Bureau (E&E), United States Agency for International Development (USAID) to enable USAID health managers, their donor partners, and host country colleagues to collect, analyze, and use data better on the HIV/AIDS epidemic in the region. Europe and Eurasia have some of the fastest growing epidemics in the world fueled primarily by injecting drug use (IDU). It is hoped that this practical guide will provide the basis for better understanding and improved response to the epidemic. It is based on activities carried out as part of an assessment of HIV/AIDS surveillance in the E&E region, which included visits to the Central Asian Republics of Kazakhstan, Kyrgyzstan, and Uzbekistan. The guide is structured as ten key steps in establishing a national HIV/AIDS surveillance system.

HIV/AIDS SURVEILLANCE IN CONCENTRATED EPIDEMICS

Most countries in the E&E region have either a low-scale HIV epidemic or one that is concentrated among particularly vulnerable populations, such as IDUs. Such epidemics require a different approach to surveillance than that employed in more generalized epidemics (Figure 1). In these settings, the purpose of surveillance is to identify the stage of the epidemic, to understand the

behaviors that are driving its spread and to introduce interventions that address those behaviors. Surveillance activities, therefore, are not an end in themselves, but rather are essential tools for the design and review of priority programs. Regrettably, current surveillance systems in the region are largely based on passive case reporting and fail to provide priority information about prevalence rates, behaviors, and size of key vulnerable

Figure 1: HIV/AIDS Surveillance in Concentrated Epidemics



Box 1: One-time Studies Supported by CDC in Central Asia

As part of its work to support the development of HIV/AIDS surveillance systems in Central Asia, CDC conducted two large-scale, one-time studies in Kazakhstan in 2002 and in Uzbekistan in 2004. These studies had similar designs in that they sought to compare an outbreak site with a similar non-outbreak site in each country. This study was carried out in Kazakhstan among IDUs in Karaganda and Temirtau, and in Uzbekistan in Yangiyul and Chirchik.

Data from the Karaganda/Temirtau study were very influential in supporting advocacy efforts for the development of a more comprehensive surveillance system in the country. This study showed that HIV prevalence was 25% in IDUs in Temirtau, a rate much higher than that among IDUs in the nearby town of Karaganda. The study also showed that women were more likely to be HIV positive than men and that HIV-positivity was associated with long-term drug use. In particular, IDUs who used a raw opiate called *khanka*, were more likely to be HIV positive than were those who injected heroin, because of significant differences in injecting practice. Those IDUs who were HIV positive were more likely to be unemployed, to have been in prison, and to have shared injecting equipment than were those who were HIV negative.

populations. In the absence of baseline data for these issues, the first priority is to collect data that can be used to design appropriate programs. The reach and quality of these programs can be monitored from program data, and surveillance data can be used to assess program coverage and to assess its effects.

STEP 1: CONDUCT A BASELINE ASSESSMENT OF THE SURVEILLANCE SYSTEM AND THE HIV/AIDS SITUATION

Before offering any technical assistance in the field of HIV/AIDS surveillance, a baseline assessment of the current situation is essential. This should cover at least two main areas. The first is the current HIV/AIDS surveillance

system. This system is likely based on passive case reporting, which usually provides data on only those who have been tested. An assessment should also include any attempts to introduce *second-generation* elements, such as biologic and behavioral surveys among vulnerable people. This assessment should include determining levels of current capacity, e.g., laboratory capacity, and principles and practices related to quality assurance and quality control.

The second area for assessment is the state of the national epidemic and response. An initial rapid collection of priority data relating to vulnerable people is worth supporting, where such data are absent. This can be done using rapid assessment and response techniques [see “Technical Guide to Rapid Assessment and Response” (TG-GAR) Internet Publication. Reference Number: WHO/HIV/2002.22].

This priority data would include HIV prevalence among vulnerable people, behavioral data from those people, and an estimation of population size. This exercise should feed into plans to develop a sustainable surveillance system and should not simply be a *hit and run* exercise. On the contrary, data from this exercise should be used to advocate for the development of an appropriate HIV/AIDS surveillance system.

STEP 2: IDENTIFY AND COORDINATE SOURCES OF TECHNICAL SURVEILLANCE EXPERTISE

Given the limited technical HIV/AIDS surveillance capacity in many countries of the E&E region, external technical assistance may be required to develop an appropriate HIV/AIDS surveillance system. If such support is requested from USAID, the Mission will require access to some level of technical expertise in order to develop terms of reference or a scope of work. In most cases, this proficiency will be available in-house in the form of a health officer. When there is no health expertise on-site, however, the Mission may need to bring in expertise from other parts of USAID or through contracting with a suitable consultant.

In the case of Central Asia, USAID has provided technical assistance to countries to develop their HIV/AIDS surveillance systems through a Participating Agency Service Agreement with another U.S. government entity, the Centers for Disease Control and Prevention (CDC). Based on this experience, key criteria have been identified that could be used to identify an organization that is able to provide technical assistance in this field (see Box 2).

In addition to international technical assistance, national-level assistance may be identified in government agencies, nongovernmental organizations (NGOs), academic institutions, and private research organizations. Technical assistance provided by USAID should be coordinated with that from other agencies, e.g., the Joint United Nations Programme for HIV/AIDS (UNAIDS) and the World Health Organization (WHO), and with surveillance on other diseases, such as tuberculosis and sexually transmitted infections (STIs).

Box 2: Suggested Criteria To Be Fulfilled by International Agency Providing Technical Assistance on HIV/AIDS Surveillance

Credible technical expertise: The organization(s) should have a proven track record and international reputation in this area. It should cover both biological and behavioral elements of surveillance.

Leadership and ability to work constructively with government: The Chief of Party should be recognized as being able to provide leadership in the field. S/he should have proven experience of having worked constructively with government systems.

Personal contacts: The organization's Chief of Party and other staff are likely to find it easier to make progress in this field if they already know key players and are already known to them.

Knowledge of country/region: The organization should know the country/region in which its staff will operate. This includes knowledge of policies, decision-making processes, and culture.

Presence in country/region: Although it may be possible to conduct one-time studies from a remote base, it may be difficult to support sustainable system development in this way.

Capacity: The organization should have spare capacity to allow it to take on these additional activities or should be able to expand its capacity in order to do so.

Connections to international standards: Although the organization may originate from one particular country, it should have strong connections with recognized international standards, such as those of the United Nations system.

STEP 3: WORK THROUGH AND STRENGTHEN NATIONAL STRUCTURES

A key feature of CDC's approach to HIV/AIDS surveillance in Central Asia has been to support national government structures to conduct surveillance activities rather than to have CDC carry out surveillance itself (see Box 3). The striking result and advantage of this approach are that governments are much more likely to

Box 3: Possible Models of Promoting Government Ownership of HIV/AIDS Surveillance Data in Central Asia

Two distinct elements are identifiable in CDC's model of seeking to promote government ownership of HIV/AIDS surveillance data. The first can perhaps be termed an authorizing model because it relies heavily on following official channels to gain a government order (*prikaz*) for the work proposed. Such orders are particularly important in highly centralized states, such as those of the former Soviet Union.

The second element might be termed an implementing model because it relies on government structures, such as AIDS centers, to actually carry out all work related to HIV/AIDS surveillance activities. This includes data collection and analysis with support from CDC.

An alternative model is being followed by the Global Fund to Fight AIDS, Tuberculosis and Malaria (Global Fund). This could perhaps be termed a funding model. The Global Fund provides money to a Principal Recipient (PR) on the basis of a proposal developed by a Country Coordinating Mechanism. Kazakhstan, Kyrgyzstan, and Uzbekistan have all had proposals for HIV/AIDS work approved by the Global Fund. In each case, the PR is a government structure. It is hoped that government may own data generated through this program, even where such studies are implemented by other agencies as subcontractors to the PR, because the funds will be controlled and managed by government.

own and use the data than if they perceive the process as having been directed by an external agency. Although this approach is time-consuming and resource-intensive, it is thought to be more sustainable in the long term. In order to work in this way, CDC has adopted a supportive, understanding, nurturing approach to its work with national governments. CDC has also utilized its own standing as a domestic U.S. government organization to present itself as a *cousin* to the government epidemiological services in Central Asia.

CDC has worked intensively with epidemiologists within AIDS centers seeking, in particular, to help them understand the value of collecting high-quality data and build a sense of pride and prestige in their work.

Although there may be a place for external studies implemented by international organizations to gather essential baseline data, such studies should complement and not undermine efforts to build up and strengthen national structures. If carried out in isolation, such studies may produce limited benefits because data may not be used in-country; further, it may be impossible for a government to sustain such research on an ongoing basis. In addition, such studies may actually be counter-productive (see Box 4). Nonetheless, there is a role for NGOs and other government structures, other than AIDS centers, within

HIV/AIDS surveillance systems. For example, narcological centers may be used as places to identify an initial population of IDUs. NGOs may also provide access to members of vulnerable populations and may also be able to provide training to government staff in appropriate ways to work with vulnerable people. For example, Population Services International (PSI) provided training to government staff on working constructively with sex workers in Tashkent, Uzbekistan.

STEP 4: BUILD ON AND REFORM EXISTING CASE-BASED SURVEILLANCE

Many countries in the E&E region rely heavily on passive surveillance systems based on HIV/AIDS. (See page 4 for a full discussion of passive surveillance systems.)

Box 4: Consequences of Failing To Coordinate with Governments?

In Uzbekistan, CDC staff reported that an NGO had gained access to a prison and had carried out serosurveillance among prisoners without ensuring informed consent. In addition, HIV tests were then carried out in a small laboratory without proven high-quality testing. Results of this work were presented in a public meeting without prior briefing of Ministry of Interior officials. As a result, the data were not used within the prison system, and other organizations found it difficult to gain access for their work in prisons.

There are significant weaknesses in this approach. Passive case reporting provides very little information on populations most vulnerable to the disease. All information is dependent on HIV-testing policies at the national and local levels, availability of test kits, and individuals' testing behaviors. These factors may lead to distorted results, particularly regarding transmission modes in countries where certain activities, such as injecting drugs, selling sex, and men having sex with men, are considered socially unacceptable and are stigmatized. Because of the long period between being infected with HIV and developing symptoms of AIDS-related illness, AIDS case reporting provides data that are five to ten years out of date. In many countries, data are derived from large-scale and (sometimes) mandatory testing, which may be discriminatory and stigmatizing. Individuals may try to be tested in a way that avoids this system, for example, through private health facilities, or they may try to avoid testing altogether, for example, through paying a fee. Many doctors within the public health system appear not to fully report.

Despite these issues, the system of case reporting can provide important information about the epidemic. For example, in Central Asia case reporting identified:

- Onsets of concentrated epidemics in Kazakhstan in 1997, in Kyrgyzstan in 2001, and in Uzbekistan in 2003
- Predominant transmission modes (i.e., through injecting drug use)
- Localized outbreaks, e.g., in Temirtau in Kazakhstan, Osh in Kyrgyzstan, and Yangiyul in Uzbekistan

Case reporting is a sensitive issue in many countries because of criticisms that countries have faced on this issue. It may be more effective therefore to recognize the value of the data gathered through this system and to improve the analysis. This work, which builds on strengths, may be linked to advocacy for reform of the system and may include supporting moves away from mandatory testing to the principle of voluntary, confidential testing supported by counseling. Policy change is certainly important, but time may be required to reform practice in line with more progressive policies. In order to achieve this, changes in particular mindsets may be necessary to overcome significant barriers to change, such as the payment of financial incentives for testing.

STEP 5: BUILD KEY LOCAL CAPACITIES

In order to work effectively through national structures (Step 3), the capacity of these institutions must be developed. This may involve training existing human resources and identifying additional ones. CDC, for example, supported the development of transport infrastructure in Central Asia by supplying AIDS centers with vehicles in which surveillance activities could be conducted.

In particular, CDC has focused on developing laboratory capacity in Central Asia (see Box 5). This activity is based on the premise that effective biological surveillance requires reliable HIV-antibody testing. Three key elements of building laboratory capacity have been identified: training of staff, establishment and implementation of quality assurance systems, and provision of technical support. The types of technical support provided include detailed guidance on technical methods and supply of essential equipment, and work on quality assurance systems.

STEP 6: EMBED NEW SURVEILLANCE SYSTEMS, FOCUSED ON BIOLOGICAL AND BEHAVIORAL DATA AMONG VULNERABLE POPULATIONS, WITHIN GOVERNMENT SYSTEMS

A wide range of terminology is used to describe HIV/AIDS surveillance systems. The term *routine surveillance* is sometimes applied to the case-based system that exists in most countries of the E&E region. Under this system, people are usually only tested when they come into contact with government services, such as health and law enforcement. Consequently, it is sometimes referred to as *passive case reporting* or a *passive surveillance system*. Under this system, testing may be carried out because a person has clinical symptoms or because the person falls within a particular subpopulation. In the past in some countries—for example, the former Soviet Union—the number of subpopulations requiring HIV testing was very large, resulting in a huge number of people tested. This approach was referred to as *total mass population screening*.

Box 5: Building Laboratory Capacity in Central Asia?

All three countries are following essentially the same system of HIV testing. This requires two ELISAs (enzyme-linked immunosorbent assays) and a Western Blot to confirm a positive HIV test. Initial ELISA tests are available in oblast-level AIDS centers. In Kazakhstan, Russian-made ELISAs are being used, and in Uzbekistan, locally manufactured kits are employed. Second ELISA tests are carried out at either the oblast or the national level. In all three countries, Western Blot is only available at the national level.

Three key issues were identified that affect the ability to carry out reliable HIV-antibody testing. These are:

- Nonavailability of test kits: This was particularly identified as an issue in Uzbekistan. Officially, there have only been shortages of ELISA kits at the oblast levels. Unofficially, however, it is acknowledged that there have also been shortages of Western Blot tests at the national level.
- Poor quality of ELISA tests: In Uzbekistan, the National Reference Laboratory has monitored the quality of local ELISA tests. Prior to 2002, it found that the sensitivity* of one of these tests (Peptoscreen) was only 30–75%. As a result of these findings, production of this test was suspended and only restarted once sensitivity could be assured to be >95%.
- Poor quality of laboratories: In Uzbekistan, the National Reference Laboratory reviewed the work of 33 laboratories in the country. Using tests with sensitivity >95% in the National Reference Laboratory, these laboratories produced a mean sensitivity of only 77%. Two laboratories had a sensitivity of 0%. Two main issues were identified, namely the poor state of equipment and nonobservance of storage and transport conditions.

The need to strengthen laboratory capacities could be reduced if UNAIDS/WHO strategies for HIV testing in resource-poor settings were followed. These provide approaches for blood safety screening, surveillance, and diagnosis based on a combination of ELISAs and rapid tests. These are cheaper and require fewer skills and less equipment than an approach that uses a combination of ELISAs and Western Blot. Rapid tests have not yet been approved for use in Central Asia, although preliminary steps to do so are under way.

* The sensitivity of a test is defined as the ability of the test to identify correctly those who have the disease; specificity refers to the ability of the test to identify correctly those who do not have the disease.

New surveillance systems are widely referred to as **second-generation** systems. Key features of such systems are that they:

- Are appropriate for the epidemic state. This means that in concentrated and low-level epidemics, they are focused on the most vulnerable groups, such as IDUs, sex workers, MSM, and prisoners.
- Are dynamic and change with the epidemic.
- Use resources where they will generate the most useful information.
- Compare both biological and behavioral data.
- Integrate all available information from different sources.
- Are action-oriented, in that they use data produced to increase and improve the national/local response.

In Central Asia, the systems being developed with CDC support are most commonly referred to as **sentinel surveillance** (see Box 6). These essentially involve identifying particular geographic sites where observations can take place and be repeated over time. This term is particularly used to refer to biologic testing, that is, of HIV prevalence. In Central Asia, however, this sentinel surveillance has also included some behavioral elements.

In low-level and concentrated epidemics, the key elements of HIV/AIDS surveillance will be:

- Cross-sectional behavioral surveys in vulnerable subpopulations
- Surveys of HIV prevalence, STIs, and other biologic markers of risk among vulnerable subpopulations
- HIV and AIDS case reporting
- Tracking of HIV in donated blood

Box 6: Strengthening Surveillance Systems in Central Asia

The first efforts to develop sentinel surveillance in Kazakhstan were supported by UNAIDS in 2002. This work was subcontracted to the Center for the Study of Public Opinion, which conducted work with four vulnerable groups—sex workers, IDUs, MSM, and prisoners. Activities consisted of unlinked biological and behavioral studies. Since 2003, this work has been supported by CDC. Two additional groups were added—people with STIs and pregnant women—and activities were focused on four sentinel sites, namely Karaganda, Pavlodar, Ural'sk (Oral), and Shymkent. In 2004, the Ministry of Health increased the number of surveillance sites to ten (including Akmola, East Kazakhstan, Kustanai, North Kazakhstan, Almaty, and Astana). They envisage that this program will be extended to cover all oblasts in 2005. In addition to these sites, there are also sentinel sub-sites within particular oblasts, e.g., in Temirtau. The expansion of sentinel sites by the Ministry of Health has proceeded faster than anticipated by CDC.

In Kyrgyzstan, CDC supported sentinel surveillance in the cities of Osh and Bishkek in 2004. In Osh, surveys were done among sex workers, IDUs, pregnant women, and STI patients. Surveillance had reportedly been carried out among 500 pregnant women in Osh in 2003. In Bishkek, work was done among three groups—IDUs, sex workers, and prisoners. Work among pregnant women, MSM, and people with STIs was scheduled to be completed by the end of 2004.

CDC started supporting sentinel surveillance in Uzbekistan in 2004 among six groups in Tashkent city and oblast. As of October 2004, data collection had been completed in Tashkent city among IDUs and sex workers, and was under way among people with STIs. Oblast data collection in Tashkent had been completed with IDUs and prisoners.

This work has produced important data concerning specific vulnerable populations. For example, in Kazakhstan, sex workers have been identified as a potentially important bridging population between IDUs and others. Sentinel surveillance among prisoners in four sites revealed relatively low rates of HIV infection (0–1%), but high levels of infection with hepatitis C (29.1–39.6%). This would seem to confirm the finding that an estimated 50% of prisoners in Kazakhstan inject drugs. Perhaps the population about whom there is least data is MSM. In 2003, CDC supported surveillance among 100 MSM in Karaganda. In this study, none tested positive for HIV.

Key features of CDC's approach in all countries include:

- Official authorization of the system through appropriate *prikaz*
- Focus on building long-term, sustainable system, implemented by AIDS centers
- Collection of linked biologic and behavioral data among six key populations—IDUs, sex workers, MSM, prisoners, people with STIs, and pregnant women
- Strong focus on building laboratory capacity, including quality assurance measures
- *Surveillance plus* approach in which results are available for participants, as is access to other services, e.g., counseling and STI treatment

In addition, in concentrated epidemics it may be advisable to extend biological and behavioral surveys to *bridging* populations and the general population in urban areas. Bridging populations are people, such as the male clients of sex workers, who may provide a route for HIV to spread from vulnerable subpopulations to the general population. Pregnant women attending antenatal clinics are often taken as a proxy for the general population.

One distinction of the approach to surveillance supported by CDC in Central Asia has been that results of biologic tests are made available to participants on a free and confidential basis, supported by appropriate counseling. Where available, this may result in a person's gaining access to appropriate treatment, such as for syphilis. CDC terms this approach *surveillance plus*. Although giving results back to participants can theoretically introduce biases into the process, *surveillance plus* is probably the most practical and ethical approach in settings where free and confidential voluntary counseling and testing services are either extremely limited or nonexistent.

In many countries of the region, the government sees itself as responsible for *routine surveillance*, but often sees other surveys as more appropriately carried out by others. One of the characteristics of the CDC approach in Central Asia has been to try to embed new surveillance approaches within existing government systems. A key step in doing so has been to develop an appropriate government order, or *prikaz*, which covers all aspects of the planned activities. As a result of this, the system and data produced are owned by the national government.

STEP 7: EMPHASIZE DATA ANALYSIS, USE, AND DISSEMINATION FROM THE START

A key feature of second-generation surveillance systems is that they are action-oriented. They are not implemented as an end in themselves but solely as a means to design and implement more effective programs. Consequently, data analysis, use, and dissemination are vital and should be planned from the start. There are many anecdotal examples in Central Asia of the positive use of data to design and amend programs (see Box 7). Although such examples are anecdotal, and these surveillance activities have started relatively recently, there is already some evidence of seeking to organize reporting more systematically. For example, in Kazakhstan, it is reported that results of sentinel surveillance are produced annually.

Box 7: Examples of Using Surveillance Data in Central Asia

In Kazakhstan...

... the finding that 50% of prisoners inject drugs has led to piloting of harm reduction programs in two prisons

... the finding that the police are major clients of sex workers has led to the introduction of a prevention program aimed at police

In Uzbekistan...

... the finding of very high HIV prevalence among IDUs in Yangiyul has led directly to PSI's plan to start programs there

Data are being used at the local, national, and regional levels. For example, data have been shared with health care departments, local authorities, and other ministries through roundtable meetings. Data have also been shared at national conferences and have been used to design national programs, for example, those submitted to the Global Fund to Fight AIDS, Malaria and Tuberculosis. Two regional conferences, in Tashkent in October 2003 and in Astana in April 2004, have been useful for sharing information among professionals and for acting as a trigger to documentation.

Despite these positive aspects, a few areas were identified that could be strengthened. These included:

- *Limited feedback of data to NGOs and members of vulnerable populations.* AIDS centers appear to prioritize *upward* reporting through Ministry of Health structures, e.g., to the national level, to oblast government, and to professional colleagues. Many NGO representatives interviewed were either unaware of findings, or they reported that information was either partial or had been received after a very long delay. Similar issues were also reported by staff of non-health government ministries.

- *Weak analytic skills, in general, and, in particular, a tendency to attribute positive changes to effects of programs.* In Bishkek, for example, it was reported that lower HIV prevalence there, compared to Osh, was evidence of more effective programs. In Osh, it was reported that case reporting/screening showed a decline in HIV prevalence in prisoners (4.2% in 2001 to 0.9% in 2003) and IDUs (6% in 2001 to 4.1% in 2003), and that this was attributable to effective programs. A reported dramatic decline in HIV prevalence in Temirtau was also attributed to effective programs without considering alternative explanations.
- *Failure to identify audiences, the information they need, and in what format.* In general, it appeared to be assumed that a report was needed to document findings. There appeared to be little evidence of seeking to identify specific audiences and their information needs. As report production takes considerable time, alternatives such as newsletters, listservs and Web postings might be considered.
- *Long delays in releasing data and in generating information.* The report of the Karaganda/Temirtau study conducted in 2002, for example, was not available in October 2004. PSI staff in Bishkek reported that they only recently received a map generated from use of the PLACE methodology in 2002–03. Although this report is of some interest, it is of little direct benefit for programming purposes because it is now so out of date. Reasons for such delays may include fear of data, the historic political legacy, an excessive focus on precision, and organizational bureaucracies.

A key feature of second-generation surveillance systems is that *they integrate all available information from different sources*. There is a tendency, however, for organizations to only value and report on work in which they themselves have been involved. This results in the loss of valuable opportunities to triangulate data. It would be very helpful to have a coordinating body to document all surveillance studies on an ongoing basis. This could be done as a periodic report, say every six to 12 months, or on a real-time basis through an updated website.

STEP 8: BUILD SYSTEMS THAT PROTECT CONFIDENTIALITY AND INCULCATE A CULTURE OF MEDICAL ETHICS

The social and political environment in the E&E region may have profound effects on the ability to develop effective HIV surveillance systems. Particular environmental elements in Central Asia include:

- Negative attitudes toward people living with HIV/AIDS and members of vulnerable populations. This is particularly true in relation to MSM.
- Potentially unstable political situations.
- Generally conservative atmosphere that is influenced by culture, attitudes, and religion.
- Restrictive policy environment. Although restrictions in this area affect all three countries, this is perhaps least seen in Kyrgyzstan, which has made a number of positive policy moves, particularly in prisons. Both Kazakhstan and Uzbekistan have introduced needle exchange programs in the community, but neither permits substitution therapy.
- Centralized decision-making structure based on Soviet-style *prikaz*.
- A strictly vertical, fragmented, biomedical health system.
- Weak culture of medical scientific ethics.
- Excessive use of identifying information and weak data controls.
- Segregation of HIV-positive prisoners. This was the norm in the past, but it is unclear the extent to which it still occurs. In Kazakhstan, for example, it is reported that there are 440 prisoners living with HIV/AIDS still in segregated facilities, but that this is by their choice, and no new prisoners are being added to those facilities.

- Mandatory HIV testing. Although all three countries have official policies that HIV testing is voluntary, it was widely reported that testing is effectively mandatory in many settings. Even in Kyrgyzstan, for example, testing is reportedly routine for prisoners who use drugs, people with tuberculosis, and those with STIs.
- Reported hostile environment to NGOs. For example, in Uzbekistan, the Soros Foundation recently failed to have its registration renewed.

Although many of these issues may need to be addressed to build an environment conducive to effective surveillance activities, a key issue relates to introducing policies and practices based on the guarantee of confidentiality for members of vulnerable populations that use services and participate in surveillance activities. Although identifying information may be required for clinical records, this ought not be the case for surveillance data. Use of identifying personal information should be minimized as much as possible. Where it is used, there should be adequate safeguards and controls in place to ensure only authorized access to the information. This applies to both paper and electronic methods of data storage. To do this effectively will require inculcating a system of medical confidentiality among health professionals. If this is achieved, it should assist in building a sense of trust between government health services, NGOs, and members of vulnerable populations.

One practical way in which CDC has supported this in Central Asia has been by introducing an ethics board or institutional review board in each country. These are registered in the United States and are responsible for reviewing and approving research and surveillance proposals before they can be carried out.

STEP 9: IDENTIFY WAYS OF MONITORING AND EVALUATING SURVEILLANCE SYSTEMS

It is important to periodically review the effectiveness of the national surveillance system to ensure that it is still appropriate for the stage and nature of the nation's epidemic. It is also important to ensure that the surveillance system is still connected to and is driving the national response.

In Central Asia, this has been done in a number of largely informal ways:

- **Self-evaluation:** Health professionals may be provided with the opportunity to attend international conferences and to make study tours in other countries and, in so doing, be able to understand more about what others are doing and to compare this with their own activities.
- **Peer review:** This may involve visits by one professional to another in the same or neighboring country, thus allowing them to compare their work and approaches.
- **Mentoring:** CDC staff may work intensively with individual health staff to build skills and competencies. For example, one CDC staff member worked intensively with epidemiologists in Osh and Bishkek on data analysis from the first round of sentinel surveillance in 2004.

STEP 10: ADD THE ICING TO THE CAKE!

Once a country has developed a basic surveillance system that is providing the basic information of HIV prevalence among vulnerable populations, risk behaviors among those people, and estimates of vulnerable population size, it is possible to extend this work in a number of different directions (see Box 8).

Box 8: Possible Expansion Areas for Surveillance Systems

Cohort studies
 Mother-to-child transmission (MTCT) surveillance
 Drug-resistance monitoring
 Monitoring of genotypes
 Modeling of incidence based on behavioral data
 Behavioral surveillance of HIV-positive people

CONCLUSIONS: LEVELS OF SUPPORT

It is likely that USAID Missions in the region will be able to provide different levels of support to HIV/AIDS surveillance activities. Factors affecting this may include:

- Length of time available to the Mission
- Funds available to the Mission
- Health-related human resources available to the Mission
- Activities being conducted by other donors

Box 9: Resources Expended in Supporting HIV/AIDS Surveillance Activities in Central Asia

MEASURE Evaluation reports that the one-time PLACE studies cost around \$50,000 per assessment, with approximately 40% of costs local and 60% international.

CDC reports that its support to sentinel surveillance in Central Asia in the first year cost \$186,000 per pilot site, excluding costs of human resources and laboratory equipment.

Table 1 gives an idea of what activities could be supported by a Mission at three levels of available resources.

Table 1. Three levels of HIV/AIDS surveillance activities that could be supported by USAID Missions in the E&E region

Resource Level			
	<i>Low</i>	<i>Medium</i>	<i>High</i>
Time available to Mission	<2 years	2–5 years	>5 years
Funds available (for illustrative purposes only)	<\$250,000 per year	\$250,000–\$1 million per year	>\$1 million per year
Possible activities to support	<p>Baseline assessment of HIV/AIDS surveillance in the country</p> <p>One-time studies to collect priority baseline data, namely HIV prevalence and behavioral data among vulnerable populations</p> <p>One-time training activities, e.g., study tours</p> <p>Coordination and documentation of surveillance activities supported by different donors</p>	<p>As for <i>Low</i> plus:</p> <p>Contracting international HIV/AIDS surveillance technical assistance</p> <p>Intensive national capacity development, including training, laboratory strengthening, and transport</p> <p>Support national policy development, e.g., on case reporting, sentinel surveillance, and medical confidentiality</p>	<p>As for <i>Medium</i> plus:</p> <p>Cohort studies</p> <p>MTCT surveillance</p> <p>Drug-resistance monitoring</p> <p>Monitoring of genotypes</p> <p>Modeling of incidence based on behavioral data</p> <p>Behavioral surveillance of HIV-positive people</p>

